

REQUEST FOR PROPOSALS

Public engagement on a fair partnership between NHS and researchers, charities and industry on uses of NHS data

1. Summary

Understanding Patient Data (UPD) and NHS England are inviting proposals for the delivery of mixed methods public engagement and deliberation on the question: *what constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS data* (patient and operational)? Findings from this work will inform the policy development being led by the Office for Life Sciences (OLS) on realising the benefits of NHS data.

In December, OLS published the second [Life Sciences Sector Deal](#), which sets out first-steps towards ensuring the benefits of health data are realised across the country. To achieve these benefits, NHS organisations need expert guidance in reaching agreements for using health data, especially with commercial organisations. The OLS have begun detailed policy work to develop national guidance and determine the type and level of commercial and legal support NHS organisations require to enable them to maximise the benefits of any deal for patients and the public, and ensure data is protected appropriately.

We recognise that this is a sensitive policy area and that it is important that we engage the public to gather views on the use of NHS data, to get a better understanding of what matters to people, their motivations, expectations, concerns, and to use their perspectives to shape the policy framework.

We are therefore commissioning a public engagement programme to gain insight and deliberation into these issues to help the OLS better understand the public's values and attitudes towards what constitutes a fair partnership between the NHS, researchers, charities and industry on the uses of NHS data. In particular, the public engagement activities will gather feedback on different benefit sharing models and generate information on the types of assurances and safeguards that could address public concerns on the use of health data by commercial and other non-NHS organisations.

We are requesting proposals to deliver a mixed-methods public engagement programme to help shape and inform the policy development. This should seek to explore the key question "What constitutes a fair partnership for the use of NHS data?" through unpacking the different values and concerns at play when people weigh up different scenarios, recognise trade-offs and express expectations, hopes and concerns about data use within and beyond the health service.¹

We expect the public engagement programme to include the following activities:

- A series of public and patient roundtables
- A series of citizens' juries
- A nationally representative survey
- A report detailing and summarising the findings from the roundtables and deliberations

Proposal submissions should clearly set out methodology, approach, milestones, estimated timescales and proposed costs.

¹ There is a broad existing literature on people's reasonable expectations, attitudes towards data use and consent models, which we do not wish to replicate. See <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data> for a summary.

2. Background

The ethical and fair use of health data by researchers and commercial partners can help drive improved patient outcomes, NHS efficiencies, and contribute to a thriving economy. However, patient data, and NHS data more generally, must be respected and protected, used in line with people's reasonable expectations and only where there is a public benefit, such as contributing to the latest data-driven scientific advances in healthcare. NHS organisations may currently be entering into agreements allowing third parties use of data they steward, but without a clear national policy framework for these partnerships. Gaps in commercial and legal expertise mean that some NHS organisations may need support to maximise the benefits they can secure for the NHS and for patients.

The second Life Sciences Sector Deal makes a commitment to publish more detail on such a policy framework and plans for a centre of commercial and legal expertise. The framework will build on the five high-level principles set out in the Sector Deal that NHS organisations would be expected to adhere to when approaching agreements for the sharing of healthcare data for research and by commercial organisations. It will aim to help the NHS adapt to the ever-increasing need to share data between different parts of the healthcare system and with the research and private sectors to tackle serious healthcare problems through data-driven innovation. This imperative to enable access to data means we must put in place an appropriate policy and delivery structures to ensure the NHS and patients receive a fair share of the benefits, and no more than their fair share of risk, when health data is made available for purposes beyond direct individual care.

The OLS has completed its first full round of stakeholder engagement with NHS organisations, health data and public engagement experts (including the charitable sector), and industry. It plans to publish the first version of the full framework later this year, with the content (including updates to the original principles) to reflect outputs from ongoing stakeholder engagement and the deliberative public engagement work proposed in this Request for Proposals.

It is imperative that this engagement is done robustly and thoroughly, building upon good work that has already taken place across the NHS data and digital agenda. We believe that public support for the OLS policy framework is paramount and, without it, it will not be possible to realise the full potential of health data and the benefits it can bring to patients and the NHS. Given how complex and sensitive the policy issues raised are, we consider that a deliberative approach to engagement will deliver the most useful insights from which to iterate the policy framework developed by the OLS.

3. Scope of proposed activities

We are looking for proposals for a programme of activities geared towards exploring the potential benefits and risks of commercial data-sharing agreements to patients and the public, including the respective roles that the NHS, researchers and commercial partners play in the healthcare innovation 'ecosystem'; and testing the contours of public acceptability around the different benefit-sharing models. To this end, proposals should deliver:

- **Public and patient roundtables:** a series of 3-5 roundtables to seek early input on the proposed framework. These roundtables can be used to shape the following engagement activities.
- **Design, recruitment and facilitation of weekend citizens' juries:** a series of 3 juries to meet over a weekend in distinct locations in the UK to consult on the models for industry-NHS collaboration identified by the OLS policy framework. The citizens will be drawn from rural

and urban locations in the areas specified and reflect a demographic diversity of the UK population. Members of the juries should come from local populations and reflect a representative spread of different perspectives. There should be 50-60 participants in total, drawn from the general public together with experts to provide insight into the key issues.

- **Nationally representative survey:** This should be developed and undertaken following the deliberative process, if appropriate and in consultation with the oversight group, to explore the findings with the wider public.
- **A workshop** to present the findings.
- **A report** to summarise the findings from the engagement activities.

The above activities will complement stakeholder engagement which has been carried out by OLS, such as industry and health experts' roundtables.

Additional information:

- **Oversight group delivery:** All materials and information provided for the engagement activities will be sense-checked by an independent oversight group, comprised of experts, UPD, NHS England and the OLS will convene this group.
- **Materials for the jury and roundtables:** The OLS, NHS England and UPD will work together with the chosen suppliers to develop content, which we would expect to work with the supplier to develop into materials for the jury and roundtables. These materials will be externally published with the final supplier's report to ensure transparency and mitigate bias.
- **UPD commentary:** UPD intend to author a commentary piece, drawing upon the report produced by the supplier to highlight key emerging issues.
- **Topic areas:** This project has a specific focus on the practical data sharing issues, tensions and trade-offs that arise when entering into a fair partnership with the NHS. As such it will not cover general issues such as consent models, or engagement on high-level principles.

4. Budget and Timeline

We expect proposals to be costed to a budget of no more than £80,000 (including VAT and expenses). Please include details of the budget in the proposal.

The project will start from the date of the contract being awarded. We expect this work to be completed around the end of August 2019, although precise timescales will be determined in consultation with the commissioned partner and with the OLS. We are open to dialogue with the selected partners as to the best/most appropriate way to arrange this work plan.

5. Proposals

Proposals must be submitted by **17.00 on Friday 7th June** to the primary contact set out below.

All questions related to the RFP should be addressed to the primary contact below via email. Questions will be collated and circulated as a Q&A to all suppliers submitting proposals.

The primary contact for this request for proposals is:

Natalie Banner
Understanding Patient Data
Wellcome Trust, 215 Euston Road
London, NW1 2BE

Email: n.banner@wellcome.ac.uk

Phone: 020 7611 8235

6. Prospective supplier guidelines

Independent proposal

By submission of a proposal, prospective suppliers warrant that the prices in the proposal have been arrived at independently, without consultation, communication, agreement or understanding for the purpose of restricting competition, as to any matter relating to such prices, with any other potential supplier or with any competitor.

Costs incurred by prospective suppliers

This document relates to a Request for Proposal only and not a firm commitment from UPD or NHS England to enter into a contractual agreement. UPD and NHS England will not be held responsible for any costs associated with the production of a response to this Request for Proposal.

Selection criteria

The selection of the preferred supplier will be at UPD and NHS England's discretion. In making the decision we anticipate considering the following factors (listed in no particular order and not intended to be exhaustive):

- Understanding of the brief and objectives of this project
- Quality of methodology and approach
- Previous experience and understanding of healthcare and/or data
- Previous experience and understanding of public engagement/deliberation
- Fit of approach proposed to achieve the goals of the project
- Perceived value for money
- Expertise of the supplier to deliver the project on time and to budget

7. Who is commissioning this research

Understanding Patient Data supports better conversations about the uses of health information. Its aim is to explain how and why data can be used for care and research, what's allowed and what's not, and how personal information is kept safe. We are an independent initiative set up and hosted by the Wellcome Trust. Further information about UPD can be found at <https://understandingpatientdata.org.uk>. Prospective suppliers are encouraged to visit the website to gain an insight into UPD's information resources and summaries of existing public attitudes research. Understanding Patient Data is contributing around 50% of costs for this research.

The Nuffield Foundation and the Ada Lovelace Institute are also providing resource by way of project management time and public deliberation expertise in-kind.

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The Office for Life Sciences (OLS) champions research, innovation and the use of technology to transform health and care service. OLS is part of the Department of Health and Social Care and the Department for Business, Energy & Industrial Strategy.